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EMERGING FROM OUT OF THE SHADOWS? SERVICE USER AND CARER INVOLVEMENT IN SYSTEMATIC REVIEWS

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Abstract

The systematic review methodology literature refers to the importance of involving stakeholders, including service users and carers, in the research. However, compared with other aspects of the methodology, this aspect of conducting systematic reviews is under-developed and the practice of involvement appears highly variable. This article draws on the experience of working with service users and carers in one systematic review to review the barriers to participation and the components of effective involvement. It suggests that quality standards can be identified for service user and carer involvement in systematic reviews, which will benefit policy and practice development.

Keywords:

systematic reviews, service users, carers, participation, involvement

Introduction

Systematic reviews are a core component of the drive within the modernisation agenda in the UK (DH, 1998) towards consistent quality in public provision. The impetus towards more evidence-based policy and practice in social care has raised their profile as a means of judging the effectiveness of interventions, mirroring longer established practice within medicine and healthcare. Using an explicit and reproducible methodology for the systematic identification, quality appraisal and synthesis of knowledge from a variety of sources (Macdonald, 2003), systematic reviews increasingly contribute to the development of a more evidence-based approach to policy making (Boaz et al., 2002) and to research-led educational development and curriculum design (Burgess, 2004). Systematic reviews of learning and teaching in key curriculum areas, commissioned by the Social Care Institute for Excellence (SCIE) to support the introduction of new social work degrees in the UK from 2003 onwards, form part of this trend.

In parallel, the modernisation agenda's emphasis on accountability, and on services that are needs-led and responsive, requires the involvement of service users and carers in strategic and individual case planning and evaluation. Thus, in determining what is effective in student learning in professional education it is logical to involve all stakeholders, including users (Burgess, 2004). In research and in service development, all knowledge production should be answerable to users and carers (Pawson et al., 2003). Such a view mirrors the perspectives of service users and carers themselves. They have long argued that participation is central to the development of research and practice that reflects and addresses their own needs and concerns (for example, Crepaz-Keay, 1997; Lindow, 1999; Morris, 1994; Peck and Barker, 1997; Pilgrim, 1998; Read and Wallcraft, 1992).

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The link between these drivers resides in the knowledge that service users and carers possess and in the challenge of determining how best to facilitate their participation. In searching for areas in which social sciences and social policy can contribute to the development of systematic review methodology, rather than simply mirror evidence-based medicine, sharing experience of service user involvement may offer a distinctive characteristic (Boaz et al., 2002; Wallace et al., 2004). However, there are few guidelines within the systematic review literature on such involvement.

This paper evaluates the researchers' experience of involving service users and carers in a systematic review of knowledge on learning, teaching and assessment of law in social work education. The research comprised a systematic review of international published and unpublished research, together with a survey of education practice in the four countries of the UK. The methodology and findings are reported in detail elsewhere (Braye and Preston-Shoot et al., 2005; Braye et al., 2005). This paper, in developing the conceptual framework for service user and carer involvement, illustrates how such involvement may inform the process and content of systematic reviews. A further benefit for social work may lie in informing service user and carer involvement in other forms of research and in the education and training of students and practitioners.

Locating Service User and Carer Involvement in Systematic Review Methodology

SCIE (2003), whilst keen to outline minimum requirements rather than to dictate methodology, highlights stakeholder involvement, especially that of service users, in knowledge reviews and practice surveys. This involvement may encompass setting the review's terms, evaluating evidence and making recommendations. Equally, in recognition that service user and carer knowledge represents one of five sources of social care knowledge (Pawson et al., 2003), systematic reviews should draw on their narratives and materials when making policy and practice recommendations. Additionally, the degree to which published and grey literature contains evidence of service user and carer involvement might be one of the quality criteria used when determining what weight should be attributed to any study.

Another framework for systematic reviews (NHSCRD, 2001) refers briefly to service user and carer involvement when discussing the expertise of the review team, and recommends the establishment of an advisory group, which should include consumer perspectives and potential users of the review. This group should be consulted on what questions the review should address, what the relevance and potential usefulness of review findings might be, and how the findings might be disseminated.

Other guidelines (Jackson and Waters, 2004) similarly advocate the formation of an advisory group that includes consumers (defined as including 'recipients' of policy), with particular emphasis on the inclusion of 'vulnerable and marginalised people' to ensure that the conclusions of the review are relevant to their interests. The tasks for the group might include decision-making on the focus of the review, its sought outcomes, the methods employed, interpretation of the data and dissemination.

Wallace and colleagues (2004) argue that stakeholder involvement can enable decisions to be tested about the focus of a systematic review and findings to be scrutinised against expert views from service users, practitioners and managers. In their view an expert panel, including consumer groups alongside academics, government officials and others, should advise reviewers on the research protocol and on such decisions as the inclusion criteria, although final decisions will rest with the researchers.

This aspect of systematic review methodology parallels drivers in research more generally where, in order to render research more accessible, relevant and utilised, the active involvement of service users and carers in developing research questions and shaping the research process is encouraged (Beresford, 1997; DH, 1999; Oliver, 1992; Ward, 1997). Indeed, the research

governance framework for health and social care (DH, 2001) requires that people using services, or their representatives, be involved wherever possible in the design, conduct, analysis and reporting of research.

Examples of service user participation in systematic reviews, however, are difficult to find in the literature. A survey of Cochrane Review Groups, responsible for the prioritisation of subject areas for systematic review in healthcare, found variable involvement by consumers (defined as patients, carers and members of patient/consumer organisations) as members of the groups and argues for a more consistent consumer influence on their agendas and activities (Kelson, 1999). Macdonald (2003) refers to the inclusion of diverse sources of evidence and knowledge, including service user studies, but does not mention service user involvement when focusing on the methodology of systematic reviews. Whilst it is not uncommon to refer to the involvement of 'research users' in consultation on reviews, the concept of 'research user' does not consistently extend to including 'end users' of the interventions being reviewed, leading Shaw and colleagues (2004) to argue that the current interpretation is too restrictive.

To the authors' knowledge there has been no systematic enquiry into the involvement of service users in systematic reviews, but examples from health and social care research, in which the ethos of participation is otherwise well established, demonstrate a rather equivocal picture, with unresolved questions about levels of involvement, visibility, types of participation, partnership and control.

Levels of Involvement

References to consumer perspectives and contributions can be somewhat oblique, appearing almost an afterthought to the contributions of researchers, information scientists and policy-makers. Similarly, their involvement appears restricted. In this respect, the framework for involvement proposed by SCIE (2003) appears slightly more extensive than that offered by NHSCRD (2001). Boaz and colleagues (2002) offer a similar analysis, suggesting that systematic review methodology oscillates between exclusion and participation in relation to service user and carer involvement. Arguably their analysis reflects this oscillation or ambivalence. They advocate that service user involvement in defining research questions strengthens systematic review methodology but this claim is left undeveloped. Moreover, when they discuss the development of standards for systematic reviews - such as using protocols, focusing on specific questions, and appraising the quality of literature prior to synthesising findings - service users and carers are invisible. A similar ambivalence may be reflected in the observation (Pawson et al., 2003) that the chances of reaching consensus on developing quality standards for service user and carer knowledge are slim.

Boaz and Ashby (2003) argue that quality appraisal can include seeking advice from peers and potential research users through steering groups and committees. However, the ambivalence that surrounds involvement is reflected when they discuss fitness of purpose, quality assessment of literature and utility or relevance to policy and practice but do not specifically identify a role here for service users and carers. Such ambivalence about participation led Temple and colleagues (1996) to refer to a glass ceiling. Service user involvement goes so far and no further, raising questions about incorporation, power and influence.

(In)visibility

In examples of systematic reviews, service users' perspectives lack visibility. Beverley and colleagues (2004) appear not to have involved visually disabled people when considering gaps in health information and identifying information needs. They do observe that future research should attempt to involve visually disabled people actively within the research process. However, they do not comment on why visually disabled people were not included in their systematic review. McInnes and colleagues (1999), updating a systematic review on nursing management of leg ulcers, appear not to have used a consultative or advisory group. Yet service user involvement could have helped counter some of the problems encountered, for example the paucity of

evidence on effective care and patient perspectives. Campbell and colleagues (2003) appear not to have involved service users in the generation of research questions in their synthesis of qualitative research on patients' experiences of diabetes care. They do suggest testing the relevance of data synthesis by presenting it to groups of patients and others, but do not provide detail of whether or how this was done in their study. A review of patient education in chronic disease management (Cooper et al., 2001), whilst exploring benefits to patients, did not involve them in framing or interpreting the outcomes of the review. Clarke (2001) does not appear to have used a consultative group, yet the involvement of service users and practitioners could have generated ideas relevant to the evaluation of in-service training in social services.

Trevithick and colleagues (2004), in reporting on a systematic review of communication skills teaching in social work education, do not mention a consultation process involving practitioners, academics or service users. Sellick and Howell (2003), in a review of foster care practice that drew both on published research and on a survey of practice, do not refer in their discussion of methodology to direct discussions with, or involvement of, foster carers or young people. Their consultation appears to have engaged principally with agency staff. People using mental health services appear not to have been consulted in a systematic review of the implementation of the Mental Health Act 1983 (Wall et al, 1999) despite their strong stakeholder interest in the operation and review of this legislation.

The invisibility of service users and carers in some systematic reviews mirrors that within research more broadly. For example, Pithouse and Scourfield (2002) saw service user involvement as valuable but not feasible within the time frame for their study on social work students' readiness for practice. Randall (2002) argues that evidence-based practice needs stronger, more credible partnerships but refers only to those between researchers and practitioners. The disillusionment he refers to, derived from historical one-way traffic between researchers and practitioners, could equally be said to apply to that between researchers and service users.

Types of Participation

In other studies, participation has been sought but the models developed have had limitations. Pawson and colleagues (2003) facilitated a workshop for consultation with service users and the development of "constructive consensus". However, this appears to have focused only on the researchers' emerging typology of types of knowledge. Consultation with service user groups on the development of quality standards for assessing knowledge appears to have been limited. Crisp and colleagues (2003) discuss potential sources of information on assessment skills teaching in social work education, but appear only to have consulted with a very limited number of practitioners and service users, and then only with respect to a draft report.

Wilson and colleagues (2004) held two consultation groups with foster carers and one group with young people. Participants were asked to comment on key findings from their study of research in foster care. The groups were designed to explore some of the main research findings found in the literature in order to deepen understanding of the issues involved and to consider whether the literature fitted with user perspectives. Walter and colleagues (2004), considering the use of research in social care practice, held four consultation seminars and seven interviews. Although they engaged principally with managers, practitioners, educators and regulators, intermediary organisations and other participants are referred to. It is possible that these included organisations of service users, especially as one such organisation was included amongst the seven interviews. Participants were asked to discuss key questions, which included the role of service users in research utilisation.

Participation as achieved in these research projects is essentially a one-off opportunity to engage with service users. Although notes were sent to participants for comment or correction (Walter et al., 2004) or short extracts from their contributions included in the final report (Wilson et al., 2004), their involvement did not evolve as the projects unfolded. More systematic participation

was offered by Rees and colleagues (2004) who, in their review of HIV health promotion and men who have sex with men (MSM), worked with an advisory group that included practitioners and representatives of MSM groups. The group worked with the reviewers at key stages of the review, influencing significant decisions relating to the scope and development of the project, and enhancing its relevance to policy and practice.

The value of stakeholder involvement, including that of carers, has been found in important differences between how they defined effectiveness and cost-effectiveness of provision compared with definitions in the literature (Arksey et al., 2004). Knowledge from different sources, including material and opinion from service users, carers and their organisations, provided added value here.

Partnership and Control

Arguing that quality standards must have the support of service users as well as providers and knowledge producers (Pawson et al., 2003) is very different from positioning service users and carers centrally in the development of such standards. Participation offers limited, if valuable (at least to the researchers) involvement in systematic reviews. It may be questioned whose priorities are reflected and the degree to which service users and carers benefit. A different approach would configure service users and carers as research partners, from problem identification, through project planning and data collection, to analysis and dissemination (Pawson et al., 2003) or envisage user-led reviews (Pawson and Boaz, 2004). Both approaches see this broader, more active involvement as strengthening research usefulness and subsequent utilisation.

The relative absence of either approach in the systematic review literature contrasts markedly with the picture in other forms of research, where anti-oppressive or emancipatory approaches (Everitt et al., 1992) challenge how research has traditionally been conducted. Such approaches centrally position service users and carers because they hold relevant knowledge and expertise and may construct issues in informative ways (Fisher, 2002; Oliver, 1992). Indeed, Randall (2002) argues that the inflated power of professionals has obstructed the development of knowledge. Emancipatory approaches seek not just enlightenment but material changes in social relations and policy influence (Lloyd et al., 1996; Oliver, 1992). One objective of partnership is the creation of a community of enquirers (Everitt et al., 1992), engaged in dialogue about definitions, strategy, analysis and dissemination. This is not participation in a pre-shaped agenda but a reciprocal relationship where knowledge, skill and experience are shared in developing ideas, challenging assumptions, formulating issues, and understanding data (Lloyd et al., 1996).

A variety of leading and supportive roles has been found in a survey of "lay" involvement in health care research for example (EPPI-centre, 2004). In a systematic study, Oliver and colleagues (2004) identify a range of factors promoting consumer involvement in setting health research agendas and priorities. Baxter and colleagues (2001) found a range of examples of lay involvement in research across a range of public sectors, including social care, and were able to identify significant elements of user ownership and control. Elsewhere, service users were involved in a 'whole system event' using appreciative inquiry methodology into hospital discharge (Reed et al., 2002). Three workshops were held during and between which stakeholders planned the research, collected data, generated 'provocative propositions', and developed action plans. The authors argue that the process of appreciative inquiry generates fresh thinking - ideas and debates that can be treated as findings. Barnes (1993) reports on research where service users and carers were involved as partners and co-workers, although the purpose of the research was not jointly defined, and where priority was given to perspectives held by stakeholders with least power. She demonstrates the learning derived from this research partnership in shaping the development of an action project in community care provision.

Why, then, should systematic reviews be any different? The answer lies perhaps in part in unfolding debates about sources of knowledge and ways of knowing, which themselves influence how the purpose and conduct of reviews are conceptualised. Solesbury (2001, p5) defines

systematic review as “methodologically rigorous exercises in assessing the findings of previous cognate research in order to synthesise the results”. This raises several complex questions. What is methodological rigour? What are the criteria for assessment? What counts as research? How is synthesis conducted? With its origins in health care, systematic review has arguably been associated with an evidential threshold that values experimental research over other forms of research, and research in general over other sources of evidence (Nutley et al., 2002). With a key objective of reducing bias in evaluating evidence, the emphasis is upon identifying reliable, quantifiable outcomes that can be generalised to populations. Within such a model, experimental research design, especially the ‘gold standard’ of randomised controlled trials, is seen as making a unique contribution to knowledge through its ability to demonstrate cause and effect (Oakley, 2000). There is little room here for the involvement of service users, other than as research subjects.

In contrast, the Higher Education Funding Council for England (HEFCE, 1999) includes in its definition of research the generation of ideas leading to new or substantially improved insights. In social care, research is located as one of five, non-hierarchical, sources of knowledge, which include knowledge from service users (Pawson et al., 2003). Across public policy more broadly there is recognition that experimental research can only answer a limited range of questions (Evans and Benefield, 2001) and that building an evidence base in health and public policy involves engaging with the entire repertoire of social science and health research, and beyond it, with policy documentation, conceptual critique and personal testimony (Pawson et al., 2004). As systematic review moves beyond a research tradition of scientific positivism to engage with qualitative research and other knowledge sources, seeking meaning rather than statistics (Baxter et al., 2001), researchers have had, and will continue, to adapt and develop its methodology (Boaz et al., 2002; Pawson et al., 2004). Service user involvement may be seen as one such development, or ‘work in progress’.

A Systematic Review of Teaching, Learning and Assessment of Law in Social Work Education

In commissioning the systematic review of knowledge on the teaching, learning and assessment of law in social work education, the Social Care Institute for Excellence required the researchers to demonstrate how service user and carer perspectives would be reflected in their work. The draft protocol addressed this requirement by proposing two conferences. The intention was for the research to be collaborative and inclusive, with service users and carers, alongside other stakeholders such as practitioners, managers and educators, acting both as a reference group and as active research participants. The perspectives of service users and carers, and the experience of practitioners, managers and educators, further triangulated with findings from the literature, would lead to a rounded view of the issues to be considered in education practice.

Conferences, or workshops and seminars, are a useful way of involving stakeholders in devising recommendations (Harrison, 1999), reflecting on and supplementing collected data, and beginning a process of action planning. They can act as a counter-balance to the use of research for political agendas by those who have the power to use that knowledge (Truman, 1999). As with focus groups (for example, Home, 1996; Walmsley, 1990; Walton, 1996), coming together can enable service users to feel more comfortable in contributing than might be the case in individual interviews. They may be able to act as a support system for each other, gaining encouragement to speak truth to power on difficult or sensitive topics.

The two conferences were to serve different purposes at key stages of the research. The initial conference would have two objectives: first, to seek views on the content and process of the study, finalising the research questions and concluding the protocol; second, to consider participants’ perspectives on law in social work education, and on law in social work practice. The second conference would also have two objectives: first, to evaluate the data obtained from the systematic literature review and practice survey, reviewing emerging findings and making recommendations for the final report; second, to consider the broader implications for education,

practice and subsequent research. Participants became an influential reference group to which the researchers presented their plans and later their findings for review. Participants also actively contributed their perspectives on the relationship between law and social work, how they saw social workers practising within the legal framework, and what this means for student learning. Creative thinking (Home 1996) and new perspectives emerged. How was this achieved?

A number of key factors, both before and during the events, contributed to the good outcomes achieved from the conferences. Successful task achievement is inherently bound up with group process, and it was important to invest in both these aspects of the meetings, drawing in no small measure on experience and understanding of groupwork, as well as upon service user and carer best practice guidelines. Groupwork theory (see for instance Doel and Sawdon, 1999) shaped the practice approach adopted in this systematic review, for instance when considering group membership and how task and process is affected by the stage a group has reached in its development. It was equally relevant when thinking about how to engage group members in the task, for example by using smaller working groups and structured techniques.

Conference composition

The researchers took the decision to invite a broad range of participants, aiming for a heterogenous group. Oliver and colleagues (2004) comment on the importance of 'purposeful outreach', to invite collaboration, and in this case contacts were made in a number of ways, drawing on both formal and informal networks and prioritising contact with organisations of rather than for service users. It was anticipated that the diversity of perspectives would result in a level of dialogue and debate that would enrich both process and outcome. An alternative would have been to run separate conferences, convening service users, carers, practitioners and educators in more homogenous groupings. This would have had the advantage of providing more obvious sources of support for participants, but at the cost of the stimulus that results from diversity. Nevertheless, anticipating potential dynamics of power and influence in the heterogenous groups, care was taken to ensure that service users and carers were well represented. They were in fact the majority group, with 15 participants identifying themselves as working from a service user or carer perspective, alongside 16 who came from a mix of other stakeholder perspectives (practitioners, educators, policy makers). Service users included young people with experience of public care, older people, parents with experience of child protection intervention, disabled people with experience of using services both on their own behalf and as parents, people with learning disabilities, mental health service users and advocacy groups. It was decided to invite all participants to both conferences, but to facilitate (through a flow of information, as detailed below) those who could, or wished to attend only one or the other. Care was taken, at the start of the second conference, to ensure that the joining stages of the group eased new participants into the process, whilst preserving the established group identity of those who had attended previously.

The researchers also offered choice of avenues for participation. One group preferred not to attend the conferences but to receive written information and subsequently work in a separate appointment with one of the researchers to share their perspectives. It was important to recognise that large meetings would not necessarily facilitate the contributions of all potential participants, and not to exclude through inflexible adherence to this particular format for involvement.

Resources

Lynch (2004) suggests that responsibility for involvement should be allocated. Service user and carer participation was prioritised as a key aim of the systematic review, with resources dedicated to achieving it. One member of the research team took primary responsibility for enlisting the involvement of service users and carers, acting as a point of information and contact both for communication about the project and the individualised practicalities of facilitating attendance. These were sometimes substantial, and required proactive organisation, both by the researchers and by the service users themselves. The venue was checked for accessibility in the context of individuals' specific needs, which were identified in advance, and close attention paid to the

question of comfort on the day. In addition to researcher time to undertake these negotiations, money was also set aside to meet the costs of travel and special transport, accommodation and fees related to attendance. The issue of appropriate reward for service users' time has been widely aired (Levin, 2004; Roe and Wenman, 2004) and Wilson and colleagues (2004), for example, offered vouchers or cash as payment for their participation in a similar project. It was self-evident here that individuals, or their organisations, should be paid for their time, immediately in cash when required.

Preparation, information and agenda setting

Service users and carers, through the first conference, were involved early on in the process to develop the research (see also Home, 1996), in recognition that plans need to reflect service users' and carers' concerns and priorities (Harding and Oldman, 1996). It was important, if this was to be achieved, that service users and carers were fully informed about the issues to be debated, and could undertake any preparatory work, thinking or consultation. Information sent out ahead of the first conference, coupled with an introductory presentation on the day, was designed to ensure that participants were fully briefed and had sufficient understanding of the project and its context in order to participate. It was important to establish a clear sense of purpose, and of the role that participants were being invited to play. When new members attended the second conference, original aims were revisited and everyone was reminded of previous work (see also Reed et al., 2002). Following both conferences, detailed notes were circulated (as by Walter and colleagues, 2004) for verification, and any amendments were incorporated in the final version. It was important to establish a culture of feedback and transparency, so that participants knew what happened to their contribution (Harding and Oldman, 1996). Care was taken to ensure that all participants received information in a format accessible for them, involving electronic, paper and taped communications.

Non-hierarchical relationships

In both conferences researchers presented themselves as facilitators rather than as experts. The knowledge, experience and expertise of those present was valued, both verbally and non-verbally, on the day and through its impact on the formulation of research instruments and findings. However, more traditional hierarchical approaches to research production and relationships were also present (Oliver, 1992). The basic methodology was never an open issue for discussion - decisions on what to research and how to collect data had already, to a large extent, taken place before the first conference. The researchers shared their expertise to progress research objectives taken from the commissioning organisation rather than to facilitate a research process (Lloyd et al., 1996). This inevitably placed limits on the extent to which an emancipatory research model (Everitt et al., 1992) could be adopted. Nevertheless, any flexibilities that existed were fully exploited, to maximise the level and extent of partnership on offer. Thus the first conference generated fresh ideas about key issues: where the researchers might look for material; what questions should be included in the practice survey questionnaire, telephone interviews and focus groups; what criteria should be used to judge the quality of research identified in the systematic literature search. In the second, conference participants reflected on the themes identified by the researchers from both the practice survey and the research review, often offering angles for exploration and sometimes clear views on ways forward for educators faced with choices about how best to facilitate learning. Their perspectives contributed substantially to the commentary on the data in the final report, which was nonetheless the result of analysis by the researchers and was not circulated for final comment.

Relative status of viewpoints

Temple and colleagues (1996) highlight the issue of how knowledge is perceived and ranked. Sources of knowledge may be triangulated but presentation and dissemination of the findings may elevate expert judgements. Wilson and colleagues (2004), for example, inserted only short extracts from service users in their final report. Baxter and colleagues (2001), in reviewing factors that facilitate effective participation in research, identify the importance of giving equal value to knowledge that derives from 'local' or personal experiences, alongside professional research

knowledge. In the presentation of the findings from this systematic review (Braye and Preston-Shoot et al., 2005) service user and carer perspectives were fully presented alongside findings from the practice survey and the literature review. This distinguishes the approach taken in this study from those reported earlier.

In the second of the two conferences, the lines of argument (Campbell et al., 2003) that appeared to be emerging from the practice survey and the literature review were presented to stakeholders for critical scrutiny and elaboration. This enabled service users and carers, for example, to emphasise, in answer to the question what law to teach social work students, the importance of making connections between different legal mandates. They stressed the importance of skills in context, and of workers appreciating how legally based interventions impact on people. They argued that workers should be both competent technicians and critical thinkers (Twining, 1967). This advanced the researchers' thinking when faced in the literature with a distinction between competence to practise and competence about practice.

Stronger than before?

An emerging theme in relation to service user and carer participation in education and training, which arguably applies equally to research, is that participation should leave people stronger, or better resourced, than before (Roe and Wenman, 2004). Strengths and resources may be seen in the widest sense, including access to training and developmental opportunities. Boaz and colleagues (2002) have suggested that researchers require training for undertaking systematic reviews. Service users and carers may also benefit from training. This was not offered in this systematic review, although individualised approaches to facilitate involvement were adopted with participants prior to each of the two conferences.

Importantly, both conferences involved not just service users and carers but also policy-makers and academics engaging in direct dialogue with each other. Emerging findings were shared more widely through focus groups with practitioners and students, and senior social services managers read the report in draft form. Whilst this was in part to rectify the absence, despite invitation, of senior managers from the conferences, the process nonetheless enabled an immediate process of change and organisational learning in response to new information (Reed et al., 2002), because service users and carers interfaced directly with those who had the power to make a policy, education and practice difference.

Group Process

Knowledge and experience of group process informed the researchers' approach to the conferences, and proved influential in facilitating the creative interchanges that took place.

The conferences progressed through different developmental stages. It was important to anticipate and to work with the flow of this development, to promote group formation and cohesion, to establish norms (Home, 1996) (even when the group had worked together before), and to manage dynamics of challenge and difference.

The role of the chair was influential in setting the tone of equality and shared responsibility for outcomes. Modelling and demonstrating respect, mutuality, listening to and valuing all contributions (Harding and Oldman, 1996), set an important standard for the conduct of the group, alongside overt negotiation of ground-rules. This progressed into a shared belief in each other's contribution to knowledge development (Randall, 2002). It was important to recognise that language is not neutral. Constructing joint understandings required care regarding the use of language (Roe and Wenman, 2004) to account for variations in understanding of concepts and terminology such as 'module' or 'systematic review'.

Some participants may have more overt participatory power than others, more voice (Walmsley, 1990). Strategies for responding to assertive participation, for example, were as important as encouraging the contributions of more reticent members. Facilitating participation involved

accepting and valuing different forms of discourse in terms of language and style, allowing time for people to talk in their own way and to be heard. Narratives of experience are an important component of participation, offering those without experience of using services to learn from the experiences of those who have. For practitioners (or educators) doing their best in sometimes hostile organisational territory, such experiences can be hard to hear, especially where they have been negative and are forcefully expressed. They require a response that moves beyond defensiveness to open-minded listening and views anger as energy and motivation, driving a desire for things to be different. Thus story-telling was valued (Roe and Wenman, 2004) and respect was accorded to individuals' self presentation. Autobiography proved a useful way to break the ice, to set the tone for sharing and deter groupthink. This had implications for the timing and pace of the conferences. Facilitators needed to be flexible about the balance of task and process activity, but also to think beyond restricted perceptions of how tasks might be achieved (through instrumental, rational discourse) and accept the contribution of personal narrative to achieving the objectives of the encounter.

For the researchers also, it was important to offer openness and critical scrutiny of oneself (Lloyd et al., 1996), involving a willingness to make one's own knowledge available, but to make oneself vulnerable and to have one's own perspective challenged and criticised.

Structuring the task

In order to create some form of structure and stimulus for creative thinking, in addition to the contributions that arose in spontaneous discussion, the researchers at times used a number of formal techniques to shape the process of discussion. Amongst these were 'miracle questions' (Reed et al., 2002) and 'three wishes'. Participants were asked to describe, for example, what would distinguish the most helpful interaction between a service user or carer and a social worker. Such structured techniques allowed participants to give statements of aspiration (Reed et al., 2002) and to turn the attention of the group to positive differences that should be sought in social work's relationship with law.

Evaluation

The pace at which participants in the two conferences worked left insufficient time for extensive reflection on, and evaluation of, the process of participation prior to the production of the final research report. As a consequence, a third conference is to be convened, offering an opportunity to meet a number of objectives: to share perspectives on the experience of participating in the systematic review; to work together on recording those experiences in formats that can be disseminated; to identify future agendas for joint work by service users, carers, educators and practitioners on law in social work education and practice.

Discussion

It is possible to identify considerable benefits from service user and carer participation in systematic reviews, but equally, inevitably, a number of barriers to participation also arise. Disseminating evidence of the benefits is important in order to create the will and experience to overcome the barriers. As the EPPI-centre (2004) identifies, lessons can be learned from successful examples of involvement in research programmes.

Benefits

Boaz and Ashby (2003) argue that a broader notion of research quality should help researchers and research users to feel confident about the use of evidence in policy and practice. They argue that service user involvement in design and conduct of the research can benefit the quality of the project. Involvement can enable achievement of a greater level of understanding through appreciating how people experience and talk about a topic (see for example, Walmsley, 1990), and can provoke different ways of thinking (Oliver et al., 2001). This links one way of knowing – drawing on people's direct experience – with other sources of knowledge (Pawson et al., 2003) drawn from empirical and theory-building research. Such involvement in systematic reviews

provides, therefore, an immediate link between practice-based evidence and evidence-based methodology with which to inform recommendations for policy and practice.

In the experience of the researchers in the study reported in this paper, service users and carer involvement helped to ensure that research was fit for purpose and its outcomes credible. The researchers would advocate the inclusion of service users and carers in each stage of systematic reviews. Their involvement should either be seen as permeating all the processes involved in systematic reviews, such as defining the protocol, identifying potentially relevant research for possible inclusion, and updating, or as a separate standard. This informs methodological rigour since they may comment upon quality and fitness of methods for purpose, messages from findings for policy and practice, and approaches to dissemination.

Equally importantly, participation can enhance the likelihood of the results being valid and useful. Lines of argument can be critiqued, a form of reality checking drawing from voices with personal knowledge of the topic in question. Preconceived ideas about what to explore or how to understand issues or interactions can be dismantled. There are inevitably different views about what constitutes good practice – in the research reported here, academic lawyers and social workers, policy-makers, service users and carers interpreted, validated and disputed each other's data.

An anti-oppressive analysis alerts researchers to considerations of power, control, expertise and authority. Inclusion can challenge hierarchical relationships. Indeed, service users are now less likely to accept authority on trust and more likely to challenge expertise and professional judgement (Webb, 2002). Participation in systematic reviews may enable researchers, policy-makers and practitioners to retain or create trust that must underpin the mandate for professional authority. For social work education, it is a logical extension of service user and carer involvement in management, delivery and evaluation of the new social work degree.

Barriers

There are nonetheless barriers to achieving levels of participation that are not constrained or tokenistic, creating an illusion of change rather than an empowering difference (Lloyd et al., 1996). Telford and Faulkner (2004), reviewing service user involvement in mental health research, note that the motivations of researchers and service users may be different, and may extend to incompatibility of ideology or conceptual frame, and that it is important to establish common ground. Barnes (1993) identifies that research timetables can promote emphasis on outcomes over process. Harding and Oldman (1996) argue that good working relationships have to be developed and worked at. Service users' unfamiliarity with research and researchers' unfamiliarity with service users' agendas can militate against good communication (Oliver et al., 2004). This takes time to build. Indeed, in the systematic review reported herein, the original proposal was to hold three conferences. This was revised down to two events on the advice of the commissioning organisation because of their tight timetable for submission of the findings. Valuing the views, experience and expertise of stakeholders was compromised by the time allowed for the project, although this was to some extent corrected by the researchers' later decision to convene a third conference for the purpose of evaluating the process. Boaz and Ashby (2003) and Lloyd and colleagues (1996) warn that sensitivity to a sponsor's requirements, for example the pressure to produce quick results, can introduce bias that conflicts with the aim of producing good quality evidence. It can jeopardise partnership work and consultation. It can influence the needs and perspectives identified (Temple et al., 1996). Reed and colleagues (2002) note that rigidity in research design can lead to alienation and reduce people's ability to respond to emerging ideas.

Another danger is that the practice of systematic reviews emphasises technology rather than process. For example, inclusion may extend only to those service user and carer organisations known to the researchers (Lloyd et al., 1996) when all groups relevant to the research should be represented (Home, 1996). Involvement may reproduce discrimination in service uptake (Olsen et

al., 1997) unless researchers go out to target communities and seek to reach hidden or marginalised service users and carers, for example through use of interpreters and community organisations. Tight time frames may limit the opportunities to establish contact with isolated people and with future rather than current service users (Temple et al., 1996), especially since participation is a lengthy process to establish. Harding and Oldman (1996), amongst others, note that carers and service users have different concerns and perspectives and that neither group is homogeneous. All this suggests that commissioners and researchers must consider how to secure the participation of a cross-section of service users and carers, those involved locally and through regional and national organisations, and the level of involvement needed for the purposes of the systematic review.

Another threat is consultation overload (Olsen et al., 1997) and cynicism (Dyson and Harrison, 1996; Lynch, 2004). Research scepticism has been an understandable reaction to occasions where involvement has not made any demonstrable difference to their situation. A "so far and no further" approach to involvement (Lloyd et al., 1996) may reinforce such scepticism by excluding service users and carers from key aspects of the research process.

Several systematic reviews (for example, Walter et al., 2004; Wilson et al., 2004) have included one snapshot consultation event. The time allowed may not permit sufficient trust to develop so that people can contribute what they are able to offer. Conferences or groups may not model non-hierarchical relationships or participants feel empowered because researchers retain control over the research agenda or questions (France, 1996). Finally, the creation of knowledge based on the perspectives of research participants is not the same as having the power to use that knowledge (Truman, 1999). Participants are not stronger as a result of their involvement because the research process has given too little attention to how they might utilise the knowledge gained as a result of their participation or interact as part of a dissemination process with those who have the capacity to effect change.

Conclusions

The issues raised and explored in this paper have extensive implications for the way systematic reviews are established and planned. More attention is needed to different interests and needs in how reviews are conceived and planned, in data collection and evaluation, and in dissemination. The researchers' experience here has shown there are ways of overcoming barriers and maximising benefits.

The emphasis placed in this paper on the contribution of groupwork knowledge and skills is deliberate. Skills of managing the process of participation are central to success but researchers do not necessarily have these skills. Learning can be transferred from focus group techniques, as well as from listening to service user and carer advocacy on what works for them. Research methods training should include content, offered by service users and carers as well as by researchers, on participation and partnership. Whilst training for service users is important (Oliver et al., 2001) it is equally essential that researchers have the opportunity to broaden their skills and experience. Thus, researchers must ensure that they have the necessary skills to involve service users and carers in research processes (Telford et al, 2004).

One way forward at the level of research policy is to develop quality standards for the involvement of service users and carers in systematic reviews. The standards would address questions such as who was involved; how did they participate; what level of involvement was offered and why; what training and support was offered; who controlled the questions to be asked; what were the outcomes of participation, both for the review and for the participants themselves. These standards could be applied when proposals for systematic reviews are being considered and when reports of the methodology, which was used, are being assessed. Such a development gives fuller acknowledgement of, and expression to, the contribution of service user knowledge *per se* to the developing evidence base, moving away from notions of an evidence hierarchy. This is not to say that such knowledge should not be subject to quality criteria, and

new approaches (for example, Campbell et al., 2003; Boaz and Ashby, 2003; Popay et al., 1998; Popay, J. and Roen, K., 2003; Pawson et al., 2004) to assessing the quality of, and synthesising, evidence from non-experimental research, conceptual and experiential sources are helpful in taking forward this agenda.

In the context of ongoing debates about sources of knowledge and the nature of evidence, the positive outcomes of embedding service users' experience and contributions at the heart of the methodology justify confidence in the future of more collaborative approaches to systematic review. Such collaborative approaches can draw on the principles and indicators of successful involvement in research (Telford et al, 2004) and education (Tew et al, 2004) by people using services and their carers. These principles and indicators begin with establishing a culture that values what service users and carers offer, and identifying the level of involvement or roles being offered. Researchers must ensure that payment, support and training is provided to maximise people's contribution, and that the language used in research meetings and documents is accessible. As Baxter and colleagues (2001) found, factors such as a will to share power, a value base that respects autonomy, the equal valuing of perspectives and the creation of a democratic structure, all make a difference to the level of participation that can be achieved.

Essentially what is involved is a process of conscientisation, seeking understanding not consensus (Harding and Oldman, 1996), and using that understanding to enrich knowledge and practice. This requires a shift of mind, metanoia, that creates the will to work for a fundamental shift in the power relations of knowledge production and dissemination.

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